liticization of aid that stands as one of the most shameful chapters in international health.

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1. Mukherjee JS. HIV-1 care in resource-poor settings: a view from Haiti. Lancet 2003;362:994-5.
2. Mukherjee JS, Farmer PE, Niyizonkiza D, et al. Tackling HIV in resource poor countries. BMJ 2003;237:1104-6.
3. Pan American Health Organization. The Haiti crisis: health risks. (Accessed March 19, 2004, at: http://www.paho.org/English/DD/PED/HaitiHealthImpact.htm.)
4. Diederich B, Burt A. Papa Doc et les Tontons Macoutes. Henri Drevet, trans. Port-au-Prince, Haiti: Imprimerie Henri Deschamps, 1986:366.
5. Farmer P, Fawzi MC, Nevil P. Unjust embargo of aid for Haiti. Lancet 2003;361 (9355):420-3.

Disparities in Health Care — From Politics to Policy

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> This first report clearly demonstrates that racial, ethnic and socioeconomic disparities are national problems that affect health care at all points in the process, at all sites of care, and for all medical conditions — in fact, disparities in the health care system are pervasive.
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> — *National Healthcare Disparities Report, as submitted to the Department of Health and Human Services (DHHS) by the Agency for Healthcare Research and Quality (AHRQ), July 2003.*[1]
>
> This first report finds that, while most Americans receive exceptional quality of health care and have excellent access to needed services, some socioeconomic, racial, and ethnic differences exist.
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> — *National Healthcare Disparities Report, as released by the DHHS, December 2003.*[2]

On December 22, 2003, as many Americans began their Christmas holidays, the DHHS released two comprehensive reports about health care, the National Healthcare Quality Report and the National Healthcare Disparities Report.[2] Four years earlier, Congress had passed a law requiring the AHRQ, which is part of the DHHS, to report annually on both the overall quality of health care and disparities in health care among racial and other groups.

It is standard procedure for government reports to go through a clearance process before their public release. The review may involve substantial back and forth among many officials, and it usually escapes public scrutiny. Moreover, federal reports, particularly those that are released during holiday periods, often attract little attention. Within weeks, however, it became widely known that although the December report on disparities in health care contained essentially the same tables of data as the report that AHRQ officials had submitted for approval six months earlier, it otherwise differed markedly from the July version. Democratic staff members in the House of Representatives who work for Representative Henry A. Waxman (D-Calif.), the ranking minority member of the House Committee on Government Reform, called attention to these differences by making public an internal AHRQ draft of the executive summary from June 2003. They issued a report on the changes as "a case study in politics and science."[3]

Members of Congress and others are more likely to read the executive summary of a detailed government report than the entire report. The June version of the executive summary of the National Healthcare Disparities Report and the July version, which AHRQ sent to the DHHS for approval, were similar but not identical. The first sentence of the July version stated that the report was "intended to provide a balanced summary of the state of disparities in the United States."[1] By comparison, the narrative in the December version was substantially rewritten to downplay the negative and emphasize the positive, including areas in which "some 'priority populations' do as well or better than the general population."[2] When these two versions are read side by side, the changes are evident both in the executive summaries and throughout the rest of the text. As

an example, the Table shows the differences between the "key findings" in the July and December versions.

In January 2004, eight Democratic members of Congress, including Waxman and the chairs of the Congressional Asian Pacific American, Black, Hispanic, and Native American Caucuses, protested the changes in a letter to Tommy G. Thompson, the secretary of health and human services. On February 10, during a hearing on the DHHS budget, Thompson "stunned" Rep. Jim McDermott (D-Wash.). Thompson responded to McDermott's question about the rewrite by announcing that "we are putting out the original report just the way it was and without any changes whatsoever." He added, "I can explain it to you, but it's not something I am very happy about. Some individuals took it upon themselves and thought they were doing the right thing. They wanted to be more positive and when it came to me I said, 'No, we put it out the way it was. That's the way it's going to be.' . . . It was a mistake made and it's going be rectified."

Later in February, "to avoid any further question," the AHRQ released "as the final report the July draft as it was sent to HHS for clearance," according to a statement from Dr. Carolyn M. Clancy, the director of the AHRQ, that is posted on the agency's Web site. "Extensive technical corrections to the tables" were included. Clancy wrote, "Over the course of the summer and fall, changes, with which I concurred, were made to the report by a broad array of staff, including AHRQ staff." In an interview, she said that the report provides "a very detailed, not-easy-to-sum-up-in-one-sentence road map for the future, and one that the department is taking very seriously."

Table. The "Key Findings" as Presented in the July and December 2003 Versions of the National Healthcare Disparities Report.

July 2003	December 2003
1. "Inequality in quality persists."	1. "Americans have exceptional quality of health care; but some socioeconomic, racial, ethnic and geographic differences exist."
2. "Disparities come at a personal and societal price."	2. "Some 'priority populations' do as well or better than the general population in some aspects of health care."
3. "Differential access may lead to disparities in quality."	3. "Opportunities to provide preventive care are frequently missed."
4. "Opportunities to provide preventive care are frequently missed."	4. "Management of chronic diseases presents unique challenges."
5. "Knowledge of why disparities exist is limited."	5. "There is still a lot to learn."
6. "Improvement is possible."	6. "Greater improvement is possible."
7. "Data limitations hinder targeted improvement efforts."	

The controversy over the editing of the National Healthcare Disparities Report has focused attention yet again on problems with health care for racial and ethnic minorities in the United States.[4] Although not all the evidence is equally convincing, disparities have been well documented in many areas, such as cardiovascular care, cancer care, human immunodeficiency virus (HIV) infection and AIDS, mental health services, receipt of immunizations for influenza and pneumococcal disease, and renal disease and kidney transplantation.[4] There are disparities in access to various medical procedures as well as in the frequency of having health insurance, the frequency of having a usual source of medical care, and the rates of hospitalizations that are potentially avoidable. The dispute has also focused attention on the risks of either overstating or understating the real problems related to disparities. Both overstatement and understatement can undermine the credibility of the federal government. Downplaying the magnitude of disparities may also make it less likely that Congress will provide sufficient funding for research and policy initiatives.

Inequities in health care did not originate during the Bush administration and are likely to pose daunting challenges for future administrations, both Democratic and Republican. "These disparities have been going on for years," said Dr. Kevin Fiscella of the University of Rochester, who served on an Institute of Medicine committee that advised the AHRQ on the design and presentation of the report. "There was nothing political in the earlier versions of the report, nothing that pointed a finger at the Bush Administration. The original report was quite balanced. It rightfully acknowledged that disparities are a complex problem with lots of contributors and no single cause. It is a mystery to me why it was changed."

A person's health may be affected by factors related to the health care system, such as the appropriateness of care, access to care, health insurance, and language and cultural barriers between physicians and their patients. It may be affected by factors beyond the control of the system, such as a person's level of education, living environment, preferences with regard to medical care, and socioeconomic status.[4] There is controversy about the role of bias, stereotyping, prejudice, and clinical uncertainty on

the part of physicians and other health care providers. The July and December versions of the report differ in defining disparities and interpreting their significance. The July report presented "a broad array of differences related to access, use, and patient experience of care by racial, ethnic, socioeconomic and geographic groups, based on valid measures. Many of the differences presented here are large and worrisome; indeed some will argue, quite reasonably, that they constitute evidence of disparity, irrespective of a clear relationship to health outcomes."[1] The December version concluded that there was no consensus on the definition of disparities. Using essentially the same data, it stated, "Where we find variation among populations, this variation will simply be described as a 'difference.' By allowing the data to speak for themselves, there is no implication that these differences resulted in adverse health outcomes or imply prejudice in any way."[2]

Under Dr. David Satcher, the surgeon general from February 1998 to February 2002 and the assistant secretary for health during the last three years of the Clinton Administration, the DHHS established six priority areas for eliminating racial and ethnic disparities: cancer screening and treatment, cardiovascular disease, diabetes, HIV infection and AIDS, immunizations in children and adults, and infant mortality. During the Bush Administration, Thompson has made addressing health disparities "one of the Department's top priorities." The priority areas are the same as in the Clinton Administration. The DHHS has called attention to continuing disparities in the burden of illness and death among blacks, Hispanics, Asian Americans, Pacific Islanders, American Indians, and Alaska Natives and has outlined its initiatives (as described on the Web site of the Office of Minority Health). There are ongoing efforts, both within the federal government and in the academic and private sectors, to consider racial disparities as a problem related to health care quality and to involve large employers, hospitals, health care systems, health insurers, and managed care organizations in addressing them. For example, an employer with a large number of employees who are members of minority groups might require that the health insurers and health care systems it contracts with develop specific plans to look for disparities and address them. The strategy is to "target improvement efforts in those areas where performance is the worst," said Clancy, director of the AHRQ. "We've gotten a lot of very encouraging feedback. . . . Organizations are telling us that they will be using the results in this report to guide their improvement efforts."

Focusing on health care disparities has also been a priority for Senator Bill Frist (R-Tenn.), the Senate majority leader and a physician. In February, Frist and several other senators introduced legislation to address the "health care gap."[5] This legislation would require the development of standardized measures of health care quality for use in all health programs sponsored by the federal government and regular public reporting of comparative information on quality for "health disparity populations." These requirements, however, would not take effect for at least several years. Although the DHHS has yet to take a position on the legislation, Claude A. Allen, the deputy secretary of the department, said in an interview that data are "going to be key for us to be able to effectively use tax dollars to target disease and treatment. We are very supportive of efforts to gather that kind of data." One concern about the legislation is that it does not specify the sources of funding for its provisions. Senators Tom Daschle (D-S.D.) and Edward Kennedy (D-Mass.) have introduced related legislation.

According to Allen, the uproar over the National Healthcare Disparities Report "has been helpful and it has been hurtful in the sense that it has brought the attention to the wrong issue [the editing of the report]. It has been helpful that we talk about health disparities." He added, "We already know that disparities exist. The question is how do we close the gap?" Now that the National Healthcare Disparities Report is finally final, the AHRQ, the DHHS, and Congress have a lot of work to do.

1. National Healthcare Disparities Report. Rockville, Md.: Agency for Healthcare Research and Quality, July 2003. (Accessed March 18, 2004, at http://www.ahrq.gov.)
2. National Healthcare Disparities Report. Rockville, Md.: Agency for Healthcare Research and Quality, December 2003.
3. Committee on Government Reform–Minority Staff. A case study in politics and science: changes to the National Healthcare Disparities Report. Washington, D.C.: U.S. House of Representatives, January 2004. (Accessed March 18, 2004, at http://www.house.gov/reform/min/politicsandscience/example_disparities.htm.)
4. Smedley BD, Stith AY, Nelson AR, eds. Unequal treatment: confronting racial and ethnic disparities in health care. Washington, D.C.: National Academies Press, 2003.
5. Closing the Health Care Gap Act of 2004, S. 2091, 108th Cong., 2d Sess. (February 12, 2004).